Supports Intensity Scale

Guidelines for Interviewing People with Disabilities

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PART 1

Overview of the Supports Intensity Scale

The Supports Intensity Scale (SIS) is a tool designed to measure the relative intensity of support that each person with developmental disabilities (e.g., cognitive/intellectual disabilities, autism, cerebral palsy) needs to fully participate in community life. The SIS is intended to be used in conjunction with person-centered planning processes to assist planning teams in developing individualized support plans that are responsive to the needs and choices of persons with disabilities.

The SIS includes 3 sections, each of which measures a particular area of support need. **Section 1: The Support Needs Scale** consists of 49 life activities that are grouped into six domains:

Home Living	**Community Living**	**Lifelong Learning**
Employment	**Health and Safety**	**Social Activities**

Scores from this section provide two indices of support needs. The SIS Support Needs Index provides a composite score that reflects a person's overall intensity of support needs relative to others with developmental disabilities. The Support Needs Profile is a graphic plot that provides a visual graph or pattern of a person's support needs across all six life activity domains.

Section 2: The Supplemental Protection and Advocacy Scale measures 8 activities. These rankings are helpful in developing individualized support plans, but the scores from this section are *not* used to determine either of the support needs indices mentioned above.

Section 3: Exceptional Medical and Behavioral Support Needs measures support needs across 15 medical conditions and 12 problem behaviors. An underlying assumption of the SIS is that certain medical conditions and challenging behaviors predict that a person will require increased support over time. The medical and behavioral items identify important considerations for support needs planning and also indicate cases where the SIS Support Needs Index may underestimate a person's "true" overall level of support needs.

SIS *Interview and Profile Form* and the SIS *User's Manual* can be purchased from the American Association on Intellectual and Developmental (AAIDD), 444 North Capitol Street, NW, Suite 846, Washington, DC 20001-1512. Call 301-604-1340, or order through the web at http://bookstore.aaidd.org.

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PART 2

Conducting SIS Interviews

The SIS is administered using semi-structured interviews by a qualified interviewer with *two or more respondents* who know the person with a disability well. Ideally, it is preferred that the respondents be people whom the person would select and who are supportive of the person. The interviewer should be a professional who has completed at least a bachelor's level degree and has experience working in the field of disabilities.

The respondents must have known the person being rated for at least three months and have had recent opportunities to observe the person function in one or more environments for substantial periods of time. If an interviewer knows a person well, he or she can also serve as a respondent. A respondent can also be a parent, sibling, direct-care staff, or the person with a disability for whom the SIS is being completed. This booklet is intended to assist interviewers who wish to interview a person with a disability as one of the respondents.

The Benefits of Interviewing People with Developmental Disabilities

There are many good reasons to include people with disabilities/self-advocates as one of the respondents when administering the SIS. People with disabilities have unique perspectives that might not be considered by others. Including people with developmental disabilities in their own planning processes yields valuable insights. Interviewing self-advocates shows that the person's opinions and perspectives are respected and valued. Nobody likes to feel that they are simply the recipient of the opinions and judgments of others, and people with disabilities definitely want to have a voice in matters that impact their lives. Indeed, even when a person with a disability cannot express themselves verbally, there are ways they can provide information for the SIS process—body shifts and posture, utterances, smiles, eye gazes, frowns or grimaces, and so forth. Including people with developmental disabilities as respondents enables them to influence the planning process that is going to significantly impact their quality of life. Therefore, participating as a respondent in the administration of the SIS can be an empowering experience for the individual. Finally, people with disabilities can learn about themselves from participating in a SIS interview. The interview might open their eyes to life activities and types of support they have not considered in the past.

Tips for Conducting Interviews with People with Developmental Disabilities[1]

It is important to remember that people with developmental disabilities are, first and foremost, people. The language we use can sometimes offend people. It has long been

[1] Portions of this section were adapted from: *Promoting full inclusion of all people with disabilities in community life: A media guide to disability.* Published by the Connecticut Council on Developmental Disabilities.

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accepted that "person-first" language is preferred when referring to people with disabilities. Interviewers should strive to be considerate of people with a disability without being patronizing. Suggestions for interviewer behavior when interviewing people with developmental disabilities are provided below.

- Be prepared that the interview process may require additional time and patience.
- Identify yourself clearly to the person being interviewed. Explain to the individual with a disability everyone's role and reason for being present at the interview.
- Use your usual tone and volume of voice.
- Make every effort to keep your language simple and clear.
- Although you will need to use plain and concrete language, it is important to treat all adults with developmental disabilities in an age-appropriate manner.
- You may need to occasionally check to make sure that the person has understood what you are saying.
- Offer help or support in a sensitive and respectful manner.
- If the individual has difficulty speaking or uses assistive technology to communicate, allow ample time for a response. If you do not understand what the individual has said, it's OK to ask them to repeat their answer.
- When interviewing an individual who has a visual impairment, make sure to clearly identify yourself. Avoid changing positions once the interview has commenced.
- If you are conversing with someone who has a hearing impairment, speak clearly and distinctly, but do not exaggerate. Provide a full view of your mouth and talk at your usual rate and volume unless asked to slow down or speak up. Look directly at the person and speak clearly, naturally and slowly if the individual can read lips. Not all persons who have a hearing impairment can lip-read. However, those who can, rely on facial expressions and other body language to help in understanding. Show consideration by placing yourself facing the light source and keeping your hands away from your mouth when speaking.

Interviewer Etiquette[2]

It is important to look at and speak directly to the person you are interviewing. Do not talk to the person with a disability through the accompanying parent or support staff person. When interviewing people who have some communication limitations, avoid correcting them or completing sentences for them. Exercise patience and do not attempt to speak for them.

[2] Portions of this document were adapted from: *Disability Etiquette Handbook.* Authored by The City of San Antonio, Texas Planning Department, and the Disability Advisory Committee.

Do not pretend to understand. If you don't understand what a respondent is communicating, ask him/her to repeat it. Do not hesitate to restate to the person what you understood, and ask him or her to correct you or confirm that it is correct. Remember to be cautious; it may happen that you misunderstand what is said but that the person with a disability may not feel comfortable correcting you. The person's reactions will clue you in and guide you to understanding or verifying that you understood correctly. When possible, ask short questions that require short answers or a nod or a shake of the head.

Keep the SIS Scoring Key in front of the respondent. You will need to go over the scoring key several times. If the person has a significant language impairment, you may need to go through the scoring key after each item, so that the person can respond by nodding or pointing to indicate his or her response.

If interviewing a person who uses a wheelchair or has other mobility support needs, make sure you plan the SIS interview in an accessible place. You may want to verify the following:

- Are there accessible parking spaces available?
- Is there a ramp or step-free entrance?
- Are there accessible restrooms?
- Is the interview room accessible?
- Is the interview location fragrance free?
- If the interview site is inaccessible to the interviewee (e.g., steps without a ramp or a building without an elevator), have you made arrangements for an alternative interview site?
- Is the place used for the SIS interview in an office or room that ensures privacy and confidentiality?

People with disabilities use a variety of transportation services when traveling. When scheduling a SIS interview, be aware that the person may be required to make a transportation reservation 24 hours in advance of the interview. Provide the SIS interviewee/respondent with an estimated time of duration of the interview so that he or she can schedule necessary transportation for his or her return trip at the end of the SIS interview appointment.

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PART 3

Guidelines for SIS Interviews with Self-Advocates

Issues the Interviewer Must Consider

There are several considerations that SIS interviewers should take into account when interviewing people with developmental disabilities. These include:

Recognition that disability is often associated with stigma. Like all people, people with disabilities do not want to be viewed as incapable, incompetent, or devalued. Yet often, having a disability label leads to all of these. To minimize the stigma that may come with a label, some people with disabilities will try to cloak their disability, and pretend that they understand what you are asking when in fact they actually may not fully understand the question posed.

Acquiescence. People with disabilities at times have a desire to please others perceived to be in power, including, possibly, interviewers. They may not answer truthfully, but they may respond to questions in a certain manner or direction because they think that is the "expected" or "desired" response. This tendency may often contribute to "acquiescence," or the tendency to answer "yes" to questions.

Processing time. People with developmental disabilities may require additional time to process the question and formulate their response. The interviewer must ensure that sufficient time is given to respond and that respondents are not pressed unduly.

Memory difficulties. People with developmental disabilities may not recall long questions or the different rating keys of the SIS. They may have a tendency to repeat the last series of choices, or repeat to the same response for several questions. You may want to give the respondent a copy of the SIS *Interview and Profile Form* protocol so that he/she can follow along. Alternatively, you might want to give then a copy of the SIS rating system (Frequency, Daily Support Time, Type of Support) to help guide them in their responses.

SIS Interviews

When conducting SIS interviews with people with disabilities, the following guidelines are strongly recommended.

Assuring interviewer/respondent rapport. Good interviewers for people with disabilities know the person well. A SIS interviewer must ask personal questions, and the person with the disability must have a high level of rapport and trust in order to share accurate information. If a close personal relationship has not been established between

interviewer should spend a few minutes at the beginning of the interview establishing rapport with the respondent. This can be easily done by conversing with the respondent about general matters. You could ask the respondent about the weather, sports, hobbies, a job, etc. These few minutes will help reduce some of the anxiety that might be experienced by the respondent. Despite these efforts, in cases where an interviewer either does not know the person well or does not have sufficient rapport with the individual, it would be best for a trusted friend or family member to be present during the interview to restate questions and provide confirmation that the individual's responses are not being influenced by rapport related factors such as a lack of familiarity with the interviewer. In some cases, the friend or family member may end up "teaming" with the person with the disability to provide responses.

If a friend or family member accompanies the person to this interview, it is important to address SIS questions directly to the person with a disability and not to the individual accompanying him/her.

Setting the stage for the interview. The interviewer should explain the purpose of the interview by providing the following introduction:

> *My name is _____. I'm going to talk with you so that we can fill out the* Supports Intensity Scale*, or the* SIS*. I will read questions on the* SIS *and ask you to let me know the* ***kind*** *of support you need,* ***how often*** *you need that support, and* ***how much*** *support you need.*
>
> *The* SIS *includes some questions that are personal. For example, I need to ask, "What, if any, assistance you need using the restroom." It is important for me to ask all of the questions and for you to answer them the best that you can. I want to know your opinion and thoughts about the supports you need.*
>
> *There are no RIGHT or WRONG answers. Your answer to a question can be used to develop a support plan that meets your needs—nobody will talk about any of your answers unless they are working on your support plan.*
>
> *Do you have any questions about how your answers will be used? Do you have any other questions about what we are doing here?*

Explaining items. The interviewer may need to extensively describe some items to assure that the respondent with a disability understands what information is being requested. Additionally, expanded descriptions of the dimensions of *frequency, duration,* and *type of support* may need to be provided. The Supports Intensity Scale *User's Manual* includes expanded item descriptions that can serve as a starting point for an interviewer. Interviewers must do their very best to provide expanded information about what is being asked without inadvertently influencing an individual's responses. Once again, conducting

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the interview alongside a trusted friend or family member may be helpful, as such an individual may be able to effectively paraphrase different items and explain different concepts.

Validating ratings. Some people with disabilities may underestimate or overestimate their needs. It is helpful to give a real life example of the activity and discuss how much support was needed, for example, "Remember when we went shopping yesterday? What support did I (or does _____) need to provide to you? I don't think I needed to provide you any physical assistance, did I? What I remember was helping you find the items on your grocery list; you'd point to them, I'd read them, and then I'd help you find them on the shelf, and you'd put them in your basket… .". It is important for an interviewer to seek additional information or examples when the interviewer believes the support might be overstated or understated (e.g., "When you go to visit your friends and family, how do you get there?" or "Remember the time you went to see Janice and she couldn't understand you? What support did you need for Janice to understand how you wanted to cook supper?"). In fact, these types of validation procedures are probably helpful when interviewing anyone.

PART 4

Resources for Interviewers

Interviewing is both an art and a science. No one resource can provide all the information one needs to effectively interview people with intellectual and developmental disabilities. The following resources will be helpful to individuals who need more comprehensive information regarding interviewing and conducting assessment.

AAIDD. 2005. The Supports Intensity Scale. Retrieved August 15, 2008 from www.siswebsite.org.

AAIDD. 2006. The SIS Vantage newsletter. Retrieved September 22, 2008 from www.siswebsite.org/Newsletter.

City of San Antonio, Texas Planning Department, and the Disability Advisory Committee. *Disability Etiquette Handbook.*

Connecticut Council on Developmental Disabilities. *Promoting full inclusion of all people with disabilities in community life: A media guide to disability.*

Developmental Disabilities Council and the Arc of Washington. *DDD Assessment Video*. 2006. Retrieved from www.informingfamilies.org/Request_DVDs.htm.

Edgerton, R. B. (1967). *The cloak of competence: Stigma in the lives of the mentally retarded.* Berkeley, CA: University of California Press, Ltd.

Seinkiewicz-Mercer, R. and Kaplan, S. B. (1989). *I Raise My Eyes to Say Yes.* Boston: Houghton-Mifflin.

Interviewing People with Developmental Disabilities (1997). Videotape available through the National Technical Information Service (Order number AAVA20263-VNB2). Price for videotape is $95 plus a $5 handling fee. Phone: (703) 605-6000, or www.ntis.gov

Person Centered Planning. Videotape available through the National Technical Information Service (Order number AVA20271-VNB2). Price for videotape is $95 plus a $5 handling fee. Phone: (703) 605-6000, or www.ntis.gov

Perry, J. (2004). Interviewing People with Intellectual Disabilities (pp. 115-132). In E. Emerson, C. Hatton, T. Thompson, and T. Parmenter (Eds.), *International Handbook of Applied Research in Intellectual Disabilities.* West Sussex, England: John Wiley & Sons Ltd.

Thompson, J. R., Bryant, B., Campbell, E. M., Craig, E. M., Hughes, C., Rothholz, D. A., Schalock, R., Silverman, W., Tassé, M., & Wehmeyer, M. (2004). The Supports Intensity Scale (SIS): *User's manual.* Washington, DC: American Association on Intellectual and Developmental Disabilities.

SIS website: www.siswebsite.org

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PART 5

Summing Up: Ten Essential Dos and Don'ts for SIS Interviewers

DOs	DON'Ts
Do interview *two or more respondents* who know the person well.	Don't interview just one person to complete the SIS.
Do allow for extra time when interviewing a self-advocate.	Don't press them to answer more quickly or rush the self-advocate through the interview.
Do introduce yourself and others who are present at the start of the SIS interview.	Don't forget to explain everyone's role and reason for being present at the interview.
Do make sure the place where you plan to conduct the SIS interview is accessible.	Don't schedule the interview at a place that is inaccessible or inconvenient for the self-advocate.
Do encourage self-advocates to invite trusted friends and/or family members to participate in the SIS interview.	Don't conduct an interview with someone with whom you have limited rapport.
Do explain the purpose of the interview by providing the following introduction: *My name is _____. I'm going to talk with you so that we can fill out the* Supports Intensity Scale, *or the* SIS. *I will read questions on the* SIS *and ask you to let me know the* KIND *of support you need,* HOW OFTEN *you need that support, and* HOW MUCH *support you need. The* SIS *includes some questions that are personal. For example, I need to ask, "What, if any, assistance you need using the restroom." It is important for me to ask all of the questions and for you to answer them the best that you can. I want to know your opinion and thoughts about the supports you need. There are no RIGHT or WRONG answers. Your answer to a question can be used to develop a support plan that meets your needs—nobody will talk about any of your answers unless they are working on your support plan. Do you have any questions about how your answers will be used? Do you have any other questions about what we are doing here?*	Don't forget to say this!
Do follow up on responses that appear to underestimate or overestimate support needs.	Don't hesitate to probe when information seems inaccurate or inconsistent.
Do provide expanded descriptions of items to assure that the respondent understands what information is being requested.	Don't limit yourself to only the expanded descriptions provided in the SIS *User's Manual* (feel free to use you own words).
Do ask the person to repeat information that you have not understood.	Don't pretend to understand something you do not understand.
Do consult additional resources on interviewing person with disabilities.	Don't get discouraged if an interview does not go as well as hoped—incomplete information from a self-advocate is preferable to no information.

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